HOU/C

HOUSE OF COMMONS SESSION 1995–96

SCIENCE AND TECHNOLOGY COMMITTEE

Third Report

HUMAN GENETICS: THE GOVERNMENT'S RESPONSE

Volume I

Report and Minutes of
Proceedings

Ordered by The House of Commons *to be printed*
3rd April 1996

LONDON: HMSO
£5·10

HC231-I

JN

LIBRARY
General Collections
P
6490
22501698384

HOUSE OF COMMONS SESSION 1995–96

SCIENCE AND TECHNOLOGY COMMITTEE

Third Report

HUMAN GENETICS: THE GOVERNMENT'S RESPONSE

Volume I

Report and Minutes of Proceedings

Ordered by The House of Commons *to be printed*
3rd April 1996

T INFORMATION SERVICE
7639B 29 APR 1996 JN
Hon/C
Wellcome Centre for Medical Science

LONDON: HMSO
£5·10

HC231-I

The Science and Technology Committee is appointed under Standing Order No 130 to examine the expenditure, administration and policy of the Office of Science and Technology and associated public bodies.

The Committee consists of 11 Members. It has a quorum of three.

The Committee has power:

(a) to send for persons, papers and records, to sit notwithstanding any adjournment of the House, to adjourn from place to place, and to report from time to time;

(b) to appoint specialist advisers either to supply information which is not readily available or to elucidate matters of complexity within the Committee's order of reference;

(c) to communicate to any other such committee and to the Committee of Public Accounts and to the Deregulation Committee its evidence and any other documents relating to matters of common interest; and

(d) to meet concurrently with any other such committee for the purposes of deliberating, taking evidence, or considering draft reports.

Unless the House otherwise orders, all Members nominated to the Committee continue to be members of it for the remainder of the Parliament.

The following were nominated Members of the Committee on 13 July 1992:

Mr Spencer Batiste
Dr Jeremy Bray
Mr Malcolm Bruce
Mrs Anne Campbell
Cheryl Gillan
Mr William Powell
Sir Giles Shaw
Sir Trevor Skeet
Dr Gavin Strang
Sir Gerard Vaughan
Dr Alan W Williams

Sir Giles Shaw was elected Chairman on 15 July 1992.

On 9 November 1992 Mr Malcolm Bruce was discharged and Mr Andrew Miller added to the Committee

On 16 November 1992 Dr Gavin Strang was discharged and Dr Lynne Jones added to the Committee.

On 7th November 1995 Cheryl Gillan and Mr William Powell were discharged and Mr Ian Bruce and Mr Patrick Thompson were added to the Committee.

The cost of preparing for publication the Shorthand Minutes of Evidence published with this Report was £2,043.24.
The cost of printing and publishing this Volume is estimated by HMSO at £1,230

TABLE OF CONTENTS

HUMAN GENETICS: THE GOVERNMENT'S RESPONSE

Page

REPORT v

PROCEEDINGS OF THE COMMITTEE RELATING TO THE REPORT xvi

LIST OF WITNESSES xvii

LIST OF MEMORANDA INCLUDED IN THE MINUTES OF EVIDENCE xviii

LIST OF APPENDICES TO THE MINUTES OF EVIDENCE xix

THIRD REPORT

HUMAN GENETICS: THE GOVERNMENT'S RESPONSE

The Science and Technology Committee has agreed to the following Report:

INTRODUCTION

1. On 18 July 1995 we published a Report on *Human Genetics: The Science and Its Consequences*.[1] This was the product of an inquiry which had lasted for over a year. The Government published its response to our Report on 10 January 1996.[2] While there was much on which the Government and Committee agreed, such as the impressive quality of genetic research and the importance of retaining the United Kingdom's scientific standing within the world research community, we were profoundly disappointed that some aspects of the Report, in particular those dealing with the wider implications of genetic science, did not appear to have received as full a consideration as we had hoped. We were so concerned by the Government's failure to construct a response which took account of the many issues which transcended existing departmental boundaries that we decided to take the unusual step of holding a further inquiry into the Government Response. We accordingly took evidence from Professor Martin Bobrow and Sir David Weatherall, two eminent geneticists who had given evidence in our earlier inquiry, to ensure our original assessment of the likely development of the science had been correct. We also examined Sir Kenneth Calman, the Chief Medical Officer, and Sir Robert May, the Government Chief Scientific Adviser, Rt Hon Stephen Dorrell MP, the Secretary of State for Health and Mr Ian Taylor MP, the Minister for Science and Technology. We are grateful to our witnesses for allowing us the opportunity to reassess our original assumptions and to explore the reasoning behind the Government Response. We also wish to express our appreciation of our specialist advisers, Professor David Porteous and Dr Bryan Sykes, who returned to assist us in this further inquiry.

2. As we noted in our original inquiry "research is progressing very rapidly ... but while the power for good that knowledge of genetics should have is acknowledged there are also frequently expressed fears that genetic knowledge could be used badly; it might support ill-founded determinism or lead to abuses of human rights."[3] Throughout our Report we stressed the need for the public to be informed about both the scientific and the social implications of genetic science. The Chief Scientific Adviser maintained that a great deal of work was being done to encourage public understanding of the science.[4] He was said to prefer a "bottom up" approach.[5] But public confidence is secured at least as much by the knowledge that developments are monitored and regulated as by education about the science involved. The regulation provided by the Human Fertilisation and Embryology Authority has meant there is broad confidence in the ethical and scientific standards of infertility treatment, even though some areas of the Authority's work are controversial. In contrast, the current unease about the Government's reaction to Bovine Spongiform Encephalopathy has shown the catastrophic results which may follow such a crisis of confidence in regulation and the science on which it is based. The concerns expressed have not been restricted to the likelihood of cross-species transmission of encephalopathies but raise completely unrelated issues such as genetic engineering.[6] It would be all too easy for public attitudes to human genetics to follow the same course.

---

[1] *Human Genetics: The Science and its Consequences*, HC(1994-95)41-I

[2] *Government Response to the Third Report of the House of Commons Select Committee on Science and Technology, 1994-95 Session*, Cm 3061

[3] HC(1994-95)41-I, para 1

[4] QQ45-47

[5] Q142

[6] 'Nature bites back', *The Guardian*, 26 March 1996, p15

3. As the Chief Medical Officer told us, the uses of genetic science in medicine will not be confined to genetic testing or screening[7], the aspects of genetic science which currently appear to raise most problems. Genetics does present us with more solutions than problems, and many of its uses will be both beneficial and non-controversial. But it is not enough for Government and practitioners to be aware of this; the public must also be made aware of it. Press reporting of human genetics has already drawn attention to the potential use of genetic testing in insurance and the use of pre-implantation diagnosis for late onset diseases.[8] More stories are sure to follow and more anxieties will be raised. It would also be complacent to deny that genetic knowledge does not have at least the potential to cause problems, such as the misuse of genetic information in insurance and employment. As we stated at the time our Report was published:

> "Public confidence is vital if genetic science its to be used to its full potential and will best be safeguarded by a robust but flexible regulatory system."[9]

4. We considered that a broadly based Human Genetics Commission could reassure the public that the width of issues raised by the uses of genetic science had been properly and impartially considered. The Commission "would be able to monitor developments in genetics and give advice to the government on the implications of such developments across a wide field."[10] This proposal was widely welcomed, both by genetic interest groups and by the scientific community.[11]

5. In the course of taking fresh evidence from the Government it became apparent that some aspects of our original proposals had been misunderstood, or perhaps made with insufficient clarity. We considered that the Human Genetics Commission should have an important advisory role, both for healthcare providers and for the Government as a whole. To ensure that its advice was well founded, the Commission would also have to have a role in monitoring current practice. While we considered that the Commission would have a regulatory function and this would mean that, eventually, it would need to have its powers defined in statute, we anticipated that it was likely that this statutory role would evolve from

---

[7] Q44

[8] 'Do your genes make you a bad risk?', *Financial Times*, 27 March 1996, p14
'Going to work on an egg', *Times Higher Education Supplement*, 15 March 1996

[9] Press Notice No 12 of Session 1994-95 (18th July 1995)

[10] HC(1994-95)41-I, para 285. We identified the following needs for advice and regulation in human genetics:

> "- genetic medicines need to be regulated;
>
> - the standards of laboratories offering screening need to be regulated;
>
> - screening programmes need to be approved before they are introduced, monitored on introduction, best practice needs to be disseminated and recommendations for the introduction or prohibition of programmes made;
>
> - there may need to be consideration of whether pre-natal testing should be offered for particular disorders;
>
> - those genetic disorders which are relevant to employment (if any) should be defined and monitored;
>
> - the law and practice of patenting needs to be kept under review and there may need to be changes to make compulsory licensing more easily available;
>
> - the effect of genetic medicine on the insurance market must be monitored and regulation proposed, if necessary;
>
> - there needs to be research into the ethical, legal and social issues raised by genetics;
>
> - public education and debate on genetics should be encouraged." (HC(1994-95)41-I, para 280).

We noted "The first of two of these tasks are technical and might fall to the Medicines Control Agency; the second could be performed by a body regulating genetic medicine as could the third and fourth. The others need a wider view." *(Ibid)*. These were to be undertaken by the Commission.

[11] See 'Genetics brought to book', *Nature*, Vol 376, p199, 20 July 1995, and Ev (Vol II), pp45, 50, 51, 54

an initial, voluntary, basis.[12] It was never our intention that this body should be responsible for the regulation of medicines produced by genetic techniques, as the Government appears to suppose; as we stated in the original Report, the Medicines Control Agency is well placed to do this, as long as it maintains the necessary expertise.[13] We see no reason why it should not do so, and we welcome the further assurances given in the Government Response.[14]

6. In rejecting our recommendation that there should be a Human Genetics Commission the Government maintained:

> "that existing bodies, both within and outside government, already cover the majority of issues for which a Commission would have responsibility."[15]

However, the Government did agree to establish a new "Advisory Committee on Genetic Testing" which would "advise on the ethical, social and scientific aspects of genetic tests and establish standards to be met by the manufacturers and suppliers of these tests".[16]

THE CURRENT SYSTEM

7. Under the current system, the following committees and organisations have been identified by the Government as dealing with aspects of genetic science:

Gene Therapy Advisory Committee
Local Research Ethics Committees
Advisory Committee on Genetic Testing
Occupational Health Advisory Committee
The Advisory Group on Scientific Advances in Genetics
Medicines Control Agency
Medical Devices Agency and
Nuffield Council on Bioethics.[17]

Some are long standing, others, such as the Genetics Working Group of the Occupational Health Advisory Committee, appear to have been established since the publication of our report. The Nuffield Council on Bioethics is an independent body. It is conceivable that it might undertake work for the Government, but that has not yet been tested.[18] In addition to these bodies, the Standing Advisory Group on Industrial Property advises the Government on patent law.

8. When we took evidence from Ministers, it became clear that the new Advisory Committee on Genetic Testing (ACGT) would be encouraged to consider the ethical and social aspects of testing in wide terms, that it would be able to draw Health Ministers' attention to issues which involved Ministers in other departments and that it "is going to find its own job definition growing" as genetic testing for employment or insurance purposes becomes more widespread.[19] However, the ACGT remains firmly under the aegis of the Department of Health, as are six of the committees identified. The Secretary of State for Health did not consider that he had a lead responsibility for considering the implications that genetic science

---

[12] HC(1994-95)41-I, para 286

[13] *Ibid*, para 176

[14] Cm 3061, para 68

[15] *Ibid*, para 7

[16] *Ibid*, para 8

[17] *Ibid*, Annex A, Q67, Q122

[18] Q125

[19] Q100, Q111, Q113, Q206, Ev (Vol II) p25

might have beyond the National Health Service[20] yet the first developments will obviously appear in the medical context. Although we were assured that the Government could deal with issues which spanned many departments,[21] the other organisations dealing with genetics are either completely outside Government or embedded in the existing Departmental structure.

9. It was our original opinion that many different aspects of genetic science would prove to be interrelated and that there would be an advantage in a Commission able to take an overview; as we said

> "Knowledge of developments in screening, say, will help suggest the effect that screening will have on the insurance market, or may suggest that research into a particular programme is needed."[22]

Sir David Weatherall agreed that genetics was "not just like any other advance in science" but "special" and "different"[23] since it was developing very rapidly and was likely to raise many complex issues[24]. He considered that the Advisory Committee on Genetic Testing "probably does not have quite a broad enough remit to cover the current complexity of the field and to have the kind of expertise in depth which it would need and the breadth of people on it to deal with the problem as it is now."[25]

10. Professor Bobrow emphasised the need for a forum in which geneticists could engage in constructive discussion with the public.[26] At present this does not exist. There is no one body to which a concerned member of the public can refer for impartial advice or express misgivings even though public concern is increasing and public confidence in the regulatory system is essential. Nor is there a body intended to act as source of knowledge with a consistent role in broadening public confidence in genetics.

11. Ministers have since indicated their willingness to reconsider the advisory structure, and we discuss their proposals below.[27] We consider that the case for a Human Genetics Commission, with a wide remit and independent of Government, remains strong. The main objective of such a Commission would be to foster public confidence and understanding. However, regulation, science policy, public understanding and public confidence are often inextricably interwoven and in practical terms the Commission's function would be to advise the Government on the broad issues raised by genetic science. The tasks we identified in our earlier Report fall into three broad categories:

- ensuring that genetic science is used effectively and responsibly in a medical context;
- ensuring that the regulatory and legal framework will allow responsible exploitation of genetic science.
- ensuring that genetic information is used responsibly in non-medical contexts.

---

[20] Q86

[21] Q65, Q162

[22] HC(1994-95)41-I, para 285

[23] QQ23-25

[24] Q15

[25] Q23

[26] Q19, Q22

[27] see paras 22-31

The existing system has mechanisms to deal with each of these points, but it is not adequate to deal with the complex interactions between them.

THE MAIN TASKS

Healthcare

12. Many of our concerns about the responsible use of genetic science in healthcare have been allayed. The Government has dealt with the most urgent problem that we identified last year, the unregulated sale of genetic tests by commercial companies, by establishing the Advisory Committee on Genetic Testing. The arrangements for evaluating screening programmes have also developed since they were announced in 1994 and the Health Technology Standing Group of the NHS R&D Panel has commissioned detailed research studies of many screening programmes.[28] One of the reasons why we recommended that the Human Genetics Commission should have a role in overseeing genetic services in the National Health Service was that it would bring much needed transparency to the system. Publication of the reports of the Advisory Committee on Genetic Testing and the Advisory Group on Scientific Advances in Genetics will go some way toward achieving that aim.

13. However, even here it seems to us there are some ethical issues which may not be sufficiently addressed. While the Advisory Committee on Genetic Testing is to be encouraged to take a broad view of its remit, it is not clear that it will be able to deal with some of the wider issues identified in our earlier inquiry, such as the privacy of genetic information. There is also the question of the guidance available to Local Research Ethics Committees (LRECs). As Sir David Weatherall said, it is desirable to have some central body to deal with research ethics in a rapidly moving field "because a Local Ethics Committee cannot do this, its job is highly pragmatic, it has got to make quick decisions and lots of them right across innumerable fields."[29] The Gene Therapy Advisory Committee gives guidance to LRECs on gene therapy, yet there is no body able to give guidance in relation to other genetic research.

14. The problems in the other areas remain acute. In our view, the most urgent problems lie in the non-medical uses of genetic screening, but there remains scope for independent advice on patenting.

Non-Medical Uses of Genetics

15. It was our view that the ability to identify genes involved in multi-factorial disorders before the treatment of such disorders could be improved might well lead to a number of social problems, particularly in insurance and employment. Although the Government Response maintained that "most of the important human disease genes are likely to be identified within the next five years"[30] it did not appear to appreciate the implications of this knowledge. Although Sir David Weatherall and Professor Martin Bobrow both thought the Government's estimate optimistic, they agreed that identification of many of the genes implicated in multifactorial disorders was likely to come in the next ten to fifteen years and would occur long before improved treatments for such disorders became more effective.[31] Professor Bobrow warned that uncertainty about the speed with which genes implicated in disease would be identified should not lead to complacency:

---

[28] Ev (Vol II), p27

[29] Q28

[30] Cm 3061, para 14

[31] QQ4-5

> "there are already extant examples of specific genes which do give predictive information which raise most of the problems of application that we will face in the future ... we need to have a developed framework very soon for dealing with the examples that already exist even though the major flood may be some years down the road."[32]

The evidence confirms our earlier view that it is certain that it will be some time before the complex links between gene, environment and diseases are fully understood. We still consider the fact that genetic tests will be available long before improved treatment or even accurate risk assessment is possible may have a number of social repercussions.

16. The Government Chief Scientific Adviser has agreed that genetic testing will allow the assessment of risk across particular groups of people even though it may not be clearly predictive at the individual level.[33] It is not unreasonable to suppose that insurers and employers may wish simply to reject those with particular genetic predispositions or load their premiums. Genetic testing has the potential to benefit those tested: as the Minister for Science and Technology said

> "There may be opportunity for a better lifestyle if one is identified as being susceptible to an hereditary problem, for example, and it may be that one tries to protect oneself by better living or available medicinal drugs."[34]

However, there is a real danger that people will be deterred from having genetic tests by fear of social or other consequences. Mr Taylor dismissed fears of a genetic underclass as ill-founded.[35] This may prove to be the case, but our concern is that there should be some mechanism to ensure that government is able to identify any problems at an early stage.

Insurance

17. Although the Government Response indicated that the Government would encourage the insurance industry and geneticists to develop an industry wide code of practice, and that it hoped to "see substantial progress within 12 months"[36] we are concerned that the Government did not fully appreciate the problems we set out. The Government Response asserted that a code might:

> "state that the taking of a genetic test would not, of itself, be taken into account for the purposes of accepting risks or setting premium rates although the positive results of such a test might be taken into account."[37]

This ignored our chief concern which was that to allow the use of genetic tests in this way might lead to "cherry picking" and the emergence of great differentials in insurance pricing. There is always a tension between the pooled risk on which insurance relies and the desire to relate premia to risk; we expect that the availability of genetic tests may exacerbate this. It is essential that the full implications of genetic science for government policy are considered. The Government Response suggests that the need to consider issues within the existing departmental structure may have led to a narrow view of the potential problems. As the Alzheimer's Disease Society said

---

[32] Q5

[33] QQ52-56

[34] Q165

[35] Q203

[36] Cm 3061, para 103

[37] *Ibid*, para 101

> "Ministers have made clear their desire to see more people plan and provide for their future ... through insurance. As yet, however, there are insufficient safeguards to prevent those people shown to be most likely to need such care through genetic testing from having their applications refused or being discriminated against through higher premiums."[38]

18. We were concerned that the Government Response might have reduced the urgency with which insurers were developing a code of practice, especially since discussions between insurers and geneticists which had been taking place at the time of our earlier inquiry appeared to have ceased. We were somewhat reassured by the Government's emphasis on the need for consultation between insurers and geneticists[39] and by Mr Taylor's statement that the development of an acceptable code of practice for the use of genetic information in insurance was something which he took very seriously, and which the Government would monitor.[40] The Minister told us that discussions with geneticists had been temporarily interrupted because "the ABI ... had taken some time to consult amongst themselves about a common position"[41] and that he expected further discussions and an announcement "before the summer".[42] We agree with the Government that an industry code of practice would be preferable to legislation. Genetic science is developing fast, and it would be far easier to adapt such a code in the light of new knowledge than it would be to revise primary legislation.

19. **Like the Government, we will wish to monitor closely the progress made in discussions between geneticists and insurers. We will also be concerned with the extent to which any agreement ensures that risk continues to be widely pooled. However, it is very likely that any code of practice will need to be amended as genetic science advances. We still consider that it would be desirable to have some body, such as the Human Genetics Commission, able to offer a timely and independent view should genetic testing appear likely to bring radical changes to the operation of the insurance market.**

Employment

20. At the time when we considered our first Report it was suggested that the provisions of the Disability Discrimination Bill should extend to those with genetic predispositions to particular disorders.[43] We did not support this, but we made recommendations intended to prevent unreasonable discrimination on genetic grounds.[44] The Government saw no reason for such measures. As the Government Response says, "any employee who is dismissed for refusing [to take a test] will generally have the right to make a complaint ... to an Industrial Tribunal."[45] However, there is no such protection for job applicants. The rejection of our recommendations has, as the Genetic Interest Group noted, meant that those already disabled cannot be discriminated against but there is no protection for those who may have genetic susceptibility to a disorder even though this may never develop.[46] The Occupational Health Advisory Committee does now have a Working Group on Genetic Screening but this reports first to the Occupational Health Advisory Committee

---

[38] Ev (Vol II) p50

[39] Cm 3061, paras 101, 103

[40] Q147, QQ167-180

[41] Q147

[42] Q174

[43] *See* HC(1994-95)41-I, para 223

[44] *Ibid* paras 224-226

[45] Cm 3061, para 99

[46] Ev (Vol II) p50-51

and, through them, to the Health and Safety Commission.[47] It is thus remote from public concerns. We consider there remains a role for an independent body, able to work across departmental boundaries and with a reasonably high profile, to consider any problems which may arise.

Patenting

21. When we reported last July we agreed that "There is ... a role for patenting in the application of the results of genetic research"[48], but we were also concerned that the patenting system might inadvertently hinder the development or application of new therapies. The further evidence we have taken suggests that the patenting system is close to our recommendation that

> " - only a combination of a gene and a known utility which is novel and not obvious should be patentable in the context of that utility; and
>
> - a combination of the same gene and a further novel utility should also be patentable."[49]

However, some areas of doubt remain. The Government was not able to clarify the extent to which the exemption allowing the use of patented material for research purposes applied, yet this exemption is widely used for genetic testing within the NHS.[50] The debate over patenting in genetics is not merely technical. Uncertainty about the application of patent law to genetics has divided researchers within and outside industry; it has also led to the expenditure of public money on pre-emptive patents which may prove valueless.[51] Unease among the research community has become intertwined with general concerns about the morality of "patenting life". The debate reached such a pitch that last session 106 of our colleagues subscribed to an Early Day Motion which proposed a ban on all patenting of DNA.[52] We appreciate that patenting law is bound by international agreements and cannot be lightly changed. However, it is open for states to press for change if there are real problems. We do not doubt the general competence of the Standing Advisory Group on Industrial Property. We note, however, that it is composed mainly of representatives from legal and producer interests and the particular problems which may be caused by the application of patenting to genetic science are likely to be too specialised for its remit. It also lacks any role in promoting public confidence. The absence of an independent body able to set out and distinguish the arguments involved in controversies over patenting has meant that there is now a substantial body of public opinion against any patenting of DNA. We still consider that there is a case for a non-technical body able to monitor the interaction between genetic science and patent law and consider any problems which may arise. Its very existence would reassure both researchers and the public that such patenting was not operating without informed comment against the public interest. Our Commission is once again a possible solution.

A NEW COMMISSION?

22. This analysis has not reopened all the topics of our previous inquiry. It has concentrated on areas in which it is easy to foresee problems or, indeed, in which problems

---

[47] Ev (Vol II) p42

[48] HC(1994-95)41-I, para 177

[49] HC(1994-95)41, para 205, Ev (Vol II), pp43-44

[50] Cm 3061, para 82

[51] Q41

[52] EDM 904, Session 1994-95

have already occurred. However, we are convinced the development of genetic science is likely to produce new problems in the future. These must be clearly addressed if we are to reap the undoubted benefits which can come from genetic science. The question is not whether there should be a body to deal with such problems but how should it be constituted?

23. When Ministers appeared before us in this follow-up inquiry they indicated that they could see a case for a body with a wider remit than the existing committees both to deal with the transdepartmental issues raised by genetic science and, by so doing, to increase public confidence that genetic science will not be misused. As Mr Dorrell said:

> "there is another element of the Commission proposal ... which I would like to suggest that more work is done on and that is the oversight cross-departmental role over the ownership of the science and the implications of the science in its broader sense, particularly looking at the moral and commercial implications of the development of that science on a broad basis. ... I intend to set in motion a review within the Government of that aspect of the Commission proposal..."[53]

The Minister for Science and Technology confirmed that the Government had

> "moved some way towards the Committee by understanding that there does need to be, in embryo, an arrangement which could give overall public confidence..."[54]

24. The establishment of the Advisory Committee on Genetic Testing and the Government's willingness to consider whether some body with a wider remit is needed is very welcome, and we appreciate Ministers' readiness to reconsider their initial response to the Committee's Report. Much will depend, however, on the membership of these bodies, on the liberty they are given to interpret their remit, and on the resources allocated to them. We were somewhat surprised to learn from Mr Dorrell that although consultation on the Advisory Committee had begun last June, he had, at the time of giving evidence, no idea of the range of expertise he wished to have represented on the Committee or the balance between lay members and those with relevant expertise.[55] We trust this indicates a willingness to consider the nature of the advisory structure needed in the light of the conclusions of this inquiry and to appoint a new commission, albeit more limited in its role than the one we first envisaged, to deal with the transdepartmental aspects of genetic science.

25. When Mr Dorrell appeared before us he warned:

> "It is important not to imagine that there is one relatively small group of people who can bring together all the expertise that is necessary to achieve the kind of both over-arching view and specialist knowledge at application level that the original proposal would have involved."[56]

Mr Dorrell also told us that the secretariats of the various existing committees were able to maintain an overview:

> "They are dealing in a scientific world where although there is a lot going on, as with all related scientific communities, there is intense dialogue within the community. The different elements of the community are aware of how the science is developing. They

---

[53] Q86
[54] Q206
[55] QQ112-114
[56] Q90

> also talk to themselves outside the context of these committees about the ethical, commercial and legal implications of the work that they are doing."[57]

There might appear to be some tension between these two propositions, but our main concerns are that there appears to be no clear line of communication between the Committees and not one of them is able to take a broad view, nor can the public identify any one of them as a source of impartial and open advice on genetic matters.

26. In our original proposal, we suggested that the Commission should be a single body able to advise on all aspects of genetic science. Since we accepted the need for the Commission to have access to specialist knowledge we envisaged that it should be independent and have the power to appoint expert assessors or technical sub-committees.[58] It is clear that the Government is not prepared to reshape the existing advisory system in this way, desirable though it would be. Since this is the case, the new body foreshadowed in our discussions with Mr Dorrell and Mr Taylor will need to have some way of ensuring it is aware of the work going on elsewhere within the government advisory structure. Mr Taylor warned

> "I do not like the word over-arching because it is a friendly word that has less friendly connotations. What does over-arching mean? If it is just a comfortable arrangement to overview what is going on, then there is some merit to it. If it is actually saying: 'No, we are going to state our position and have the power to intrude', which is a quasi-regulatory power, then I am not so comfortable until I know what the extent of those powers are."[59]

27. Whatever Mr Taylor's reservations, **if the new body proposed by Ministers is to command public confidence, it will need to have an overview of the work done within government and by other government committees dealing with matters relevant to genetics. It should also be independent and have the power to take evidence and to publish its conclusions.**

28. Mr Taylor was prepared to concede that while not all members would be members of other advisory or regulatory committees, it might be appropriate to ensure some cross-membership between committees.[60] **We consider that cross-membership between the new body to oversee genetics and existing committees would give the body a valuable source of expertise. However the body should not be confined to, or even dominated by, experts since it will have an important role in reassuring the public that ethical and social issues are being considered by those with no vested interests in the advice that is offered.**

29. In its reply to the Committee's Report the Government said

> "Health Ministers will monitor the workings of the Advisory Committee on Genetic Testing and keep the option of statutory control open."[61]

Mr Dorrell later told us that the Government was "taking a cautious and evolutionary approach to the question of legislation."[62] **We recommend that the relationship between the various committees and other bodies with power to advise on or regulate aspects of**

---

[57] Q99

[58] HC(1994-95)41-I, para 288

[59] Q157

[60] Q158

[61] Cm 3061, para 66

[62] Ev (Vol II) p25

genetics be monitored and that the proposed transdepartmental body be given more formal powers if this is necessary.

30. Mr Dorrell explained his resistance to granting regulatory powers to a Commission as follows

> "I think in a world where nobody can know how this science is going to develop over the next five or ten years, ... it would be a very bold Parliament, frankly, that gave to an unelected body a regulatory function ... I think it is one thing to ask for an Advisory Committee where the recommendations be brought to Government and ultimately to Parliament, I think it is quite another to delegate the regulatory function to an unelected body."[63]

Parliament has already conceded the right to regulate the sensitive moral issues involved in infertility treatment and embryo research to the Human Fertilisation and Embryology Authority. Under the current system, important ethical issues raised by genetic science are simply not addressed, or are dealt with behind closed doors. We trust that the Advisory Committee on Genetic Testing and the new body proposed by Ministers will have the discretion to deal with them. We are confident that, as we pointed out before, their involvement will not prevent Parliament reassuming control if it so wishes.

31. We consider the time is ripe for Parliament to consider these issues. The evidence which Ministers have given encourages us to believe they are prepared to strengthen the mechanisms for dealing with issues which transcend departmental boundaries, we hope through a body which would carry out many of the tasks of the Commission which we proposed. **We believe there should be a debate on the floor of the House on the way in which such a Commission would operate. We would welcome it soon in the context of a response to this Report.**

---

[63] Q103

PROCEEDINGS OF THE COMMITTEE RELATING TO THE REPORT

WEDNESDAY, 3 APRIL 1996

Members present:

Sir Giles Shaw, in the Chair

Mr Spencer Batiste
Dr Lynne Jones
Mr Andrew Miller
Mr Patrick Thompson

The Committee deliberated.

Draft Report (Human Genetics: The Government's Response) proposed by the Chairman, brought up and read.

Ordered, That the draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 18 read and agreed to.

Paragraph 19 read, amended and agreed to.

Paragraphs 20 to 30 read and agreed to.

Paragraph 31 read, amended and agreed to.

Resolved, That the Report, as amended, be the Third Report of the Committee to the House.

Ordered, That the Chairman do make the Report to the House.

Ordered, That the Appendices to the Minutes of Evidence taken before the Committee be reported to the House. — *(The Chairman)*.

[Adjourned till Wednesday 24th April at Four o'clock.

LIST OF WITNESSES

(VOL II)

Page

Wednesday 14 February 1996

Professor Martin Bobrow and Professor Sir David Weatherall 1

Professor Sir Kenneth Calman, Chief Medical Officer, and
Professor Sir Robert May, Chief Scientific Adviser 8

Wednesday 28 February 1996

Rt Hon Stephen Dorrell, MP, Secretary of State for Health 16

Wednesday 6 March 1996

Mr Ian Taylor MBE, MP, Minister for Science and Technology 30

LIST OF MEMORANDA INCLUDED IN THE MINUTES OF EVIDENCE

(VOL II)

Page

1. Memorandum from the Department of Health (HGRD13) 26

2. Memorandum from the Office of Science and Technology (HGRD11) 30

3. Memorandum from the Office of Science and Technology (HGRD15) 44

LIST OF APPENDICES TO THE MINUTES OF EVIDENCE

(VOL II)

Page

1. Memorandum from Professor Peter Harper and the Royal College of Physicians Clinical Genetics Committee (HGRD1) 47

2. Letter to the Clerk of the Committee from Professor Peter Harper (HGRD2) 47

3. Memorandum from the Association of British Insurers (HGRD3) 47

4. Memorandum from SmithKline Beecham (HGRD4) 48

5. Memorandum from the Nuffield Council on Bioethics (HGRD5) 49

6. Letter to the Chairman of the Committee from the Alzheimer's Disease Society (HGRD7) 52

7. Memorandum from the Genetic Interest Group (HGRD8) 52

8. Letter to the Chairman of the Committee from the Genetics Forum (HGRD9) 53

9. Memorandum from the British Society for Human Genetics (HGRD10) 56

10. Memorandum from the Royal Society (HGRD12) 57

11. Letter to the Clerk of the Committee from the Association of British Insurers (HGRD14) 58

Printed in the United Kingdom by HMSO
19585 C7 4/96 250764

ISBN 0-10-226696-4

Published by HMSO and available from:

HMSO Publications Centre
(Mail, fax and telephone orders only)
PO Box 276, London SW8 5DT
Telephone orders 0171 873 9090
General enquiries 0171 873 0011
(queuing system in operation for both numbers)
Fax orders 0171 873 8200

HMSO Bookshops
49 High Holborn, London WC1V 6HB
(counter service only)
0171 873 0011 Fax 0171 831 1326
68-69 Bull Street, Birmingham B4 6AD
0121 236 9696 Fax 0121 236 9699
33 Wine Street, Bristol BS1 2BQ
0117 9264306 Fax 0117 9294515
9-21 Princess Street, Manchester M60 8AS
0161 834 7201 Fax 0161 833 0634
16 Arthur Street, Belfast BT1 4GD
01232 238451 Fax 01232 235401
71 Lothian Road, Edinburgh EH3 9AZ
0131 228 4181 Fax 0131 229 2734
The HMSO Oriel Bookshop
The Friary, Cardiff CF1 4AA
01222 395548 Fax 01222 384347

The Parliamentary Bookshop
12 Bridge Street, Parliament Square,
London SW1A 2JX
Telephone orders 0171 219 3890
General enquiries 0171 219 3890
Fax orders 0171 219 3866

HMSO's Accredited Agents
(see Yellow Pages)

and through good booksellers

©Parliamentary copyright House of Commons 1996
Applications for reproduction should be made to HMSO

ISBN 0 10 226696 4